Mind the Gap! Advancing Data Equity to Improve Population Health Equity for People with Disabilities

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Introduction

The Center for Community Inclusion and Disability Studies (CCIDS), Maine’s University Center for Excellence in Developmental Disability (UCEDD), carries out a variety of education and research activities designed to improve the social and health equity of people with disabilities (PWD). CCIDS sought to examine the health equity of Maine’s population with intellectual and neurodevelopmental disabilities (IDD/NDD) regarding Covid-19. However, we encountered a data gap. Therefore, we examined the drivers of data gaps for people with disabilities (PWD) to make recommendations for improving their health equity by ensuring their representation in public health data, the evidence base for policymaking.

Leadership Mentors: Dr. Alan Cobo-Lewis, Ph.D., Dir. CCIDS and Susan Russell, Associate Director, CCIDS

Activities:

- Conducted data and literature searches and reviews
- Established lines of communication with Maine’s Office of Population Health Equity, Disability Rights Maine, and the Maine CDC
- Attended two webinars
- Conducted legislative research
- Authored a white paper
- Produced and presented a policy brief to Maine’s federal delegation

Figure 1. Population wellness is the aim of the 10 essential public health services and equity is at their core

Results:

- 27% of adults<sup>2</sup> and almost 20%<sup>2</sup> of children<sup>3</sup> (305,218 people)<sup>4</sup> in Maine, and 26%<sup>5</sup> of adults and 4.3%<sup>6</sup> of children (nearly 70.6 million people)<sup>7</sup> in the US have at least one disability.

Figure 2. Causative theory for health disparities experienced by PWD

- Disability data gaps hide health disparities and perspectives of PWD, perpetuating harmful biases.<sup>8</sup> <sup>9</sup> <sup>10</sup>
- 3 Types of data gaps exist for PWD. They are the lack of 1) disaggregatable data, 2) granular prevalence data, and 3) data from inaccessible surveillance tools.

Figure 3. Data equity is key to health equity

- The Americans With Disabilities Act (ADA)<sup>11</sup> is a US law that upholds civil rights protections for PWD under the 14<sup>th</sup> amendment.<sup>12</sup> Exclusion of PWD from benefits enjoyed by other US populations is illegal.
- Frameworks exist for improving data equity for PWD and for achieving equity in healthcare and health emergency planning.<sup>13</sup> <sup>14</sup>
- Health equity drives cost savings and increases self-reliance and productivity of PWD and their caregivers which can lead to health and economic gains across generations.<sup>15</sup> <sup>16</sup> <sup>17</sup>
- Health data linked with disability data provide accountability and a basis for trust in leaders who seek meaningful health progress for PWD.<sup>18</sup>

Conclusion

The collection and reporting of public health data that represent health outcomes, voices, and experiences of PWD are essential to driving down disparities, an ethically, legally, and fiscally sound goal. Data equity for PWD fosters attunement of policies and practices that drive ability rather than disability, offering PWD a fair and just opportunity to attain optimum health and to thrive in their communities.

Three major determinants must be optimized to achieve health data equity for PWD: 1) the legal data privacy framework (e.g. HIPAA), 2) interoperability of data language and systems across domains, and 3) alignment of states’ data laws & practices.

Recommendations

Twelve recommendations designed to encourage data equity for PWD were made in two general areas:

I. Achieving congruence of states’ data laws
II. Shifting mindsets around the collection & reporting of health data for PWD

References


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